



Intellectual & Developmental Disabilities Task Force

NOTICE OF MEETING AND AGENDA

The Intellectual & Developmental Disabilities Task Force will meet on Friday, February 23, 2018 at 10:00 a.m. (CT), at the Booneville-Warrick County Public Library, 611 West Main Street, Booneville, Indiana, 47601.

Task Force Members Present: Dr. Pam Wright, Trent Fox, Kathleen McAllen, Kim Milas, David Reed, Joseph Langerak, Christine Dahlberg, Julie Reynolds, Kylee Hope, Lt. Governor Susanne Crouch, Jonathan Burlison, Jason Meyer, Steve Cook, Kim Dodson, Betty Williams

Absent: Allison Taylor (Joshua Bougie attended in her place), Terry J. Stigdon (David Reed attended in her place), and Debbie Pierson.

- I. **Lt. Governor Suzanne Crouch calls meeting to order (10:00 a.m.)**
Introduction of Task Force Members
- II. **Listening Session – Facilitated by Kelly Mitchell, CEO, Southern Indiana Resource Solutions (SIRS) (10:05 a.m. – 10:55 a.m.)**

Vicki Warren, Vice President of Human Resources, the ARC of Evansville. Commented on the DSP crisis. It is difficult to recruit and retain direct qualified support professionals (DSPs) due to the low wages paid to DSPs. This leads to high turnover and inconsistent services to individuals. There are not enough DSPs to serve the individuals coming into the system. A plan needs to be developed to address the crisis. Low wages are because of the low rates the State pays. Group homes pay more because they receive cost based reimbursement. Other businesses like Target and fast food restaurants offer \$12 – 14 per hour as a starting wage. DSPs start at \$9 – 10 per hour. Suggests a solution of a waitlist to begin. Not enough DSPs are available to serve individuals in the system. Proposes standardized training developed by the state with competencies that is transferable to other qualified providers should they choose to move employment.

Rick Adams, Vice President, Benchmark Human Services. Commented regarding the revision of Indiana Code 460 IAC 6 & 7. This is the Indiana Administrative code that governs services for individuals utilizing the CIH and FSW waivers. Indiana Code 460 has not been updated in the last 15 years. In 2016, DDRS announced that they would re-write the code and the provider community was pleased. INARF provided recommended changes to the DDRS. In April, 2017 INARF was invited to participate in the State 460 Workgroup. It was clear that the desire of DDRS was to redesign 460 in a broad manner with specific information to be clarified within Bureau of Developmental Disabilities Services policy. It was announced at a final workgroup meeting that a draft of 460 would be presented in the Spring of 2018. There will be no opportunity for the workgroup or the public to provide feedback on the policies used to enforce 460. Using policy to clarify 460 can be problematic as policy can be easily changed. A specific code allows individuals and families to have a better understanding of what to expect from each service that they choose and gives providers clarity in delivering services. A code

serves as a guide during times of administrative change. Broad and weak code leads to unstable, low quality and weak services.

Cami Berkav, Parent. A parent of a 21-year-old son receiving services and is now attending Access Academy. Applied for services in 1999 and began receiving them in 2004. He is now receiving an age appropriate education and is able to communicate with doctors about many factors related to his health. He has a desire to get a diploma and become a minister. The system is not set up for post-secondary training and education options for her son and she asks that this be addressed. Community Services and behavior services while he moves out of his parent's home. There are no individuals that have supports and training. There is nothing in place for him to have trained care providers on his transition out of his home.

Kelly Barnett, Vice President of Adult Services for the ARC of Evansville. Comment regarding DSP shortage. Medicaid funding is becoming available for services but many now can't find anyone to provide the services. The state has nearly eliminated the waiting list, but there isn't enough staff to provide DSP support. Thirty years ago the rate to DSPs was competitive. Now, it's not enough and the needs are greater. The Medicaid reimbursement rates don't cover the costs.

Lisa Fisher, VP of Clinical Services at Easter Seals Rehabilitation Center, Evansville. They are a First Steps service provider. Referrals are up 17% from last year. It is anticipated that more growth will occur as a result of the opioid crisis. The system is not keeping up with the growing need. Rates for therapy services have been cut three times in the last 15 years without any increases the average amount paid per child is decreasing over time. This brings challenges in recruitment and retention. The rural areas to provide services can be a challenge. There is a decrease in the number of providers of First Steps Services. They hope for adequate billing rates for the future. Increased rates for both therapies and case management, easier and streamlined enrollment for providers, changing how services are authorized to allow for flexibility in scheduling and allowing for more services to be provided on site.

Lora Leinenbach, Executive Director of Programs, Four Rivers/DSI: There are major issues with staffing for rural day programming. Staffing and transportation is a great challenge and it is very hard to recruit quality staff. If you cannot keep ratios, you can't pull down the funds. Ratios should be addressed. Community habilitation is outside the communities where they live. This defeats the purpose because it is outside of their local communities. They would like additional funding would help to improve the quality of the programs in-house to bring and attract community members into their facility and this would help build natural supports.

Steve Sacksteder, Four Rivers /DSI. Transportation is essential to be self- dependent especially in rural communities. Limited choices. Ten counties ride solution rural transportation system provides access to those with ID/DD. Funding for public transportation has remained static. The need is steadily increasing and resources are insufficient.

Bonnie Stuckey, Parent. Bonnie is a foster parent of two nonverbal 16-year old autistic children. Two areas of concern: education and mental health services. There is no academic based education in their Life Skills classroom. One child is now enrolled at Access Academy, he

is able to communicate. Access Academy has trained staff. Smaller of the two children is stuck in life skills class in public school. Because she's smaller in size, there is not so much of a challenge. Mental Health: There is one psychiatrist available and he is not appropriate for these children.

Jim Wiltz, Psychologist at Stone Belt. There is a need for crisis supports. Much is already known about crisis supports because they were provided 2007-10. We already have baseline data. In 2014, the state contracted with the University of NH gap analysis documented the availability of services across the state. Essentially, when a crisis occurs, you are on your own. Service providers are reluctant to accept those that present challenges because there is no staff to help support.

Barbara Jackson, Instructor at the ARC of Evansville. After her mother died unexpectedly in 2011, her twin sister, Ann, came to live with her. The ARC provided resources and she eventually applied to the day program. Her sister has thrived with the qualified DSPs. There is high turnover and her sister is impacted negatively by this.

Sierra Nunez, Manager of Residential and Community Integration Services at the ARC of Evansville. Families need to be better trained about what Medicaid services cover and how best to use it. Medicaid waiver language is foreign to families and they need someone to help them understand the services are available to them. Families don't understand the roles of case managers, doesn't know the appropriate questions to ask a provider and don't know their role responsibilities or rights. Case managers tend to focus on paperwork vs training and supporting families on the waiver. Currently, case management does not meet the needs of families new to the Medicaid waiver. She suggests maybe a scorecard for evaluating the case manager to help them be more.

Tim Beitzel, Residential Director at Three River Services. Worked in this field of ID/DD and mental illness for 30 years. Foundation of service delivery are the people that provide care so it is cost effective and productive. Group homes are a cost effective part of the system. Many who live there are happy and productive and invites Task Force to come and visit. Staffing is a challenge. There are no emergency services available.

Kimberly Woerz, Manager of Adult Day Services, The ARC of Evansville. Providers will not be able to provide quality group community integration as defined in the CMS Rule at today's current reimbursement rates. Community Habilitation Group is reimbursed at the same rate as Facility Habilitation Group however Community Habilitation requires more staff, lower ratios and more competent DSPs to help. Much more difficult for one staff to provide support for four individuals staff in the community than in the facility. Trying to provide supervision to three clients to while meeting the personal care needs of one client is difficult if not impossible. More supervisory oversight will be needed to ensure that services are delivered as directed. Some individuals and families are not in agreement with all services being entirely community based – so what do we do? FSW is not a one size fits all concept. Suggest using unused funds to be redistributed to families and individuals in need supports. First Steps and FSW services for children can be limited in some areas of the state. Create a Children's waiver with a reduced budget.

Deidra Conner, The ARC of Evansville. This comment is in regard to financial stability in regard to the agencies servicing clients. The rates for Medicaid services are not sufficient to cover the costs for providers. Group home services are by the cost based reimbursement.

Day services, community based services, and non-group home residential services and others don't get cost based reimbursement. These are inexpensive critical services that are note

getting reimbursed. Without cost based reimbursement, agencies are forced to cut costs like continuing education courses, mileage reimbursement, wellness programs, and retirement contributions, administrative staff. Overhead costs are very important to provide an ethical, compliant, reliable organization. It takes funding to have a well-rounded organization to provide quality. They need to raise money just to pay the bills. They need to mentor and support families, IT and support, 1200 CARF standards are met to get reaccredited. Please consider CBF.

Johnda Knight, Community Placement Manager with the ARC of Gibson County. She has a caseload of 15. There are limited referrals from VR. Order of Selection August – January 2018, 886 individuals were deferred from services. Workshop cannot accept anyone under the age of 24. Opportunities are limited for individuals in the rural community. Lack of public transportation and a smaller pool of employers in the area makes it quite difficult. Toyota (and some of their vendors) is a great employer partner in the area. How many are falling through the cracks and missing opportunities because of OOS?

David Block, VOA: Planning and talking about a good life vs. living one. Concern is “mechanization of the system”. Things aren’t happening in the community because they don’t have the supports and the guidance it requires. Plans are sitting on shelves. Let’s think about how to give guided practice to those who want to do community work to achieve a better life.

Yvonne Martin, Mother of a 15 year old with Autism and mental illness. For the last nine months her family member has been in jail. He needs residential treatment but his IQ is too high to receive residential treatment. Can’t go to psychiatric facility because he has autism. In a time of crisis I had my son arrested. DCS removed him and he was taken to jail. Why doesn’t Indiana have a place for him?

Andrea, parent of an individual with a disability. She dropped her son off to school and had IEP meeting at school. There is a lack of passion from the teachers. Photos were passed around of alleged abuse the child received at school. She contacted CPS and met with the principal. Her son has lost a year of school. There is nothing affordable or accessible for him. She chose the option of a school Access Academy.

Susan Rinne, Retired CEO of Life Designs, Inc. Comments were focused on employment – fewer people with disabilities are employed than in other states. This has not always been the case. In the 90s the rate of employment for persons with disabilities is twice what it is today. Why? There is a need for commitment, resources and attitude. At one time, our state ranked fourth in the nation on supported employment. When everyone is expected to work, they do. Employment is an outcome of a service and not a service.

Angie Anderson, Quality and Compliance Director, SIRs. She commented on the many challenges they see. They often get demands from families who don’t understand the staffing crisis and last minute scheduling requests. Case managers demanding reports be submitted in a timely manner, meetings are rescheduled without our input – often we must choose between attending a meeting and attending to an individual. Often we get a budget with us as the provider but we haven’t even met the client. Pulling direct care out to get training and covering for them is a challenge. Having 24/7 backup is also a challenge and wages are not the only problem. Staffing is stretched.

Kelly Dora, Behavior Specialist for Warrick School Corporation. There is one big pot of money to serve ID/DD and mental health needs. The services are segregated by the State of Indiana. Put the same people in the room and desegregate services. Individuals with Autism and Developmental Disabilities do also sometimes have mental health needs.

Mary James, Customer Relations Director, SIRS. The model needs to change. Look at the silos. Often case managers are busy doing paperwork while the providers are actually doing the day-to-day case management. How can they realistically be involved in the process, know the individual and be most impactful? Behavior management needs to occur in the setting with families and direct service staff. Front line staff need to have skillsets ... it is not about developing a plan or hosting an annual training session, or being involved with a consumer with just a phone call. In the past many had specialized instruction and education degrees. Today, the majority of front line staff have no specialized training or degrees. Where is crisis support 24/7? We need to work with families to manage expectations. There is a labor shortage.

Casey DePriest, President & CEO of Optimal Rhythms & Access Academy. Provider of integrated music therapy since 2002. Knows the waiver system well. Presuming competence is important when serving individuals in the community. Students were unable to access the education system. IQ tests are all motor based tests and giving them to students with motor based difficulties. There are many children that don't respond to ABA. They have solutions to help with training and to reduce the need for behavioral needs of individuals.

Kelly Mitchell, CEO, SIRS. The Medicaid waiver system is strained and it nearing crisis. Waiver services must be viewed as support and not as a solution. A community and society cannot abdicate all aspects of life to providers. Natural Supports should not diminish as waiver support is gained. Kelly suggests that the Task Force work with ARC and other advocacy groups to develop working model that is focused on need vs. want and outcome vs. activity. We don't want to take away choice and freedom but how can we provide more continuity.

III. Review and Approval of Minutes from December 19, 2017 Meeting

There was a motion to approve the minutes and a second motion to approve. The minutes were approved.

IV. Review and Discuss Revised Task Force Vision and Values

a. Review Revisions made based on December 19, 2017 Task Force Discussion

b. Adopt Task Force Vision and Values

The Task Force adopted the revised Vision and Values:

The Vision and Values statement was revised to emphasize employment as a preferred outcome for those individuals who choose it. The Task Force approved the amended text:

Vision

- All Hoosiers are included, recognized, and supported as equal citizens, including people with intellectual and developmental disabilities.
- All Hoosiers with intellectual and other developmental disabilities have opportunities to use their gifts and talents and live a good life, with choice and control.

Values

Future community-based supports and services for Hoosiers with intellectual and other developmental disabilities will:

- Be based on strengths and respond to individual abilities, and dreams.
- Respond to individual and family needs
- Respond to individual and cultural differences.
- Recognize legal, civil, and human rights and responsibilities as citizens.
- Prioritize typical community settings and individualized approaches to support peoples' lives.
- Ensure individuals drive and control supports and resources to make informed choices about life; and honor the choices they make.
- Nurture and support family and natural supports.
- Advance and maximize community and state resources and programs to be inclusive to all Hoosiers.
- Include a wide array of supports and services that are sustainable, equitable, and available across all communities.
- ***Focus on employment as the outcome of all services, if that is the choice of the individual.***

V. Data Work Group Report – Current System: Population Served and Services
 (Julie Reynolds, Director of Strategic Initiatives, DDRS) Julie provided a comprehensive overview of data related to the population served and services in Indiana.

SEE POWERPOINT PROVIDED TO TASKFORCE MEMBERS

VI. Current Environment and Impacts on Services (discussed at December 19, 2017 Meeting)
a. Review Questions and Task Force Input from December 19, 2017 Meeting

VII. Crisis Response White Paper (Kim Dodson, Executive Director, Arc of Indiana and Steve Cook, President/CEO, INARF)
 There is a demonstrated need for crisis services in Indiana. At present, 30% of individuals have a co-occurring mental health diagnosis. There are only two providers in the state that address this. The Lt. Governor commented that it would be nice to know what not having the services are costing us today. She stated that although we always have to look at cost, but not having services is a far great cost than having it. It was asked if some members would work with Steve and Kim to develop this topic more.

VIII. Additional Agenda Items or White Paper Topics (Task Force Members)

The following topics were suggested:

Betty Williams suggested the topic of Supported decision making.

Jon Burlison suggested the following topics:

Shared living

Telehelp

DSP training portability of credentials

Improving the consumer directed family service model

Military waiver position: when deployed the child loses the waiting list spot. Something should be done to ensure when the family returns they are back in line or can maintain their position while they are away.

Money follows the person

Elimination of sub-minimum wage

Driverless autos and the legislation around it

IX. Sample Themes for Task Report (Kylee Hope, Director, DDRS)

a. Discussion of Direction and Proposed Format

Kylee Hope presented a sample design format and theme for the comprehensive plan. Feedback included suggestions from the Task Force members that included identifying what is administrative and what is legislative. Under objectives, it was suggested the action steps that are necessary be included.

X. Next Meeting – Wednesday, April 18, 2018, 11:00 am ET

Wabash Center Inc.
2000 Greenbush Street
Lafayette, IN 47904

XI. Meeting adjourn